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Are ICD recipients able to foresee if they want to withdraw therapy or deactivate defibrillator shocks?☆

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ABSTRACT

Background: Expert consensus statements on management of implantable cardioverter defibrillators (ICDs) emphasize the importance of having discussions about deactivation before and after implantation. These statements were developed with limited patient input. The purpose of this study was to identify the factors associated with patients' experiences of end-of-life discussions, attitudes towards such discussions, and attitudes towards withdrawal of therapy (i.e., generator replacement and deactivation) at end-of-life, in a large national cohort of ICD-recipients.
Methods: We enrolled 3067 ICD-patients, administrating the End-of-Life-ICD-Questionnaire.
Results: Most (86%) had not discussed ICD-deactivation with their physician. Most (69%) thought discussions were best at end-of-life, but 40% stated that they never wanted the physician to initiate a discussion. Those unwilling to discuss deactivation were younger, had experienced battery replacement, had a longer time since implantation, and had better quality-of-life. Those with psychological morbidity were more likely to desire a discussion about deactivation. Many patients (39%) were unable to foresee what to decide about deactivation in an anticipated terminal condition. Women, those without depression, and those with worse ICD-related experiences were more indecisive about withdrawal of therapy. Irrespective of shock experiences, those who could take a stand regarding deactivation chose to keep shock therapies active in many cases (39%).
Conclusions: Despite consensus statements recommending discussions about ICD-deactivation at the end-of-life, such discussion usually do not occur. There is substantial ambivalence and indecisiveness on the part of most ICD-patients in this nationwide survey about having these discussions and about expressing desires about deactivation in an anticipated end-of-life situation.

1. Introduction

Recent expert consensus statements from the Heart Rhythm Society [1] and the European Heart Rhythm Association [2] have emphasized the importance of discussing the issue of deactivation toward the end-of-life with implantable cardioverter defibrillator (ICD) recipients, and initiating such discussions before ICD implantation. Communication about ICDs at the end-of-life presents many challenges, and it is unclear if clinicians and patients routinely discuss management of ICDs at the end-of-life and the alternative modes of dying [3,4]. In several small scale studies, investigators have examined patient preferences for discussions regarding death and attitudes about deactivation of ICDs at the end-of-life [5–14]. The majority of patients want to be involved in a deactivation discussion [6,11], yet some are reluctant [7,8,14] and also uncomfortable discussing advanced directives with their families [13]. Some investigators have found that ICD recipients want to have an end-of-life discussion sooner rather than later in the illness trajectory [12], preferably prior to implantation [11]. Others reported that patients prefer such discussion be held when it is suspected that their life expectancy is decreased [6,7]. Patients have reported mixed preferences about keeping their device activated at the end-of-life. Some investigators have provided patients with hypothetical scenarios and found that the majority of patients prefer to keep the ICD active if they had a serious illness and were unlikely to survive [5,7,10], even if it meant receiving multiple shocks at end-of-life [10]. Others have found that most ICD patients favor device deactivation at end-of-life [6,9]. A recent systematic review by Russo (2011) concluded that more research regarding patient

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attitudes towards ICD deactivation is needed [15]. Thus, consensus is lacking about when ambulatory patients prefer to receive information and engage in discussions about ICD deactivation at the end-of-life.

The purpose of this nationwide cross-sectional study was to identify the factors associated with patients' experiences of end-of-life discussions, attitudes towards such end-of-life discussions, and attitudes towards withdrawal of therapy (i.e., generator replacement and deactivation) at end-of-life in a large national cohort of ICD recipients independently of psychological distress and quality-of-life. Specific aims were to 1) describe ICD patients' experiences of end-of-life discussions – and attitudes towards – such end-of-life discussions and ICD therapy at end-of-life; 2) determine the association of sociodemographic and clinical variables (i.e., gender, age, education, ICD indication, time since implantation, type of ICD, shock experience, and prior ICD battery replacement) controlling for anxiety symptoms, depressive symptoms and quality-of-life (QOL), with patient's experiences of end-of-life discussions; and 3) determine the association of these same variables with patient's attitudes towards end-of-life discussions and withdrawal of therapy at end-of-life.

2. Methods

2.1. Study Design, Sample and Data Collection

This was a cross-sectional, correlational study in which self-reported data was used. The study conforms to the Declaration of Helsinki and was approved by the Regional Ethics Committee for Human Research at the University of Linköping, Sweden. Patients were recruited from the Swedish ICD- and Pacemaker registry; a national quality database in which all recipients of cardiovascular implantable electronic devices in Sweden have been registered since the start in 1989. All adult patients eligible in the registry in 2011 ($n = 5535$) were sent an invitation to participate in the study during September to October 2012. After completing an informed consent explaining that the study was voluntary and that they could withdraw from the study at any time, the patients were mailed the questionnaire. One reminder was sent out 3–4 weeks following the first letter.

2.2. Measures and Instruments

2.2.1. Demographic and clinical variables

Socio-demographic variables collected included gender, age, marital status, and educational level. Information on clinical variables, including indication for ICD implantation, cardiac resynchronization therapy, battery replacement, and time since implantation were obtained from the Swedish ICD- and Pacemaker registry. Information on co-morbidities was self-reported. Satisfaction with the ICD, and experience of shocks was obtained through investigator-designed questions.

2.2.2. End-of-life concerns

Data on end-of-life perceptions and attitudes was collected using the "Experiences, Attitudes and Knowledge of End-of-Life Issues in Implantable Cardioverter Defibrillator Patients (EOL-ICD) Questionnaire". The instrument is a self-rated questionnaire containing three domains that measure experiences (10 items), attitudes (18 items) and knowledge (11 items) of end-of-life in ICD patients. The EOL-ICD Questionnaire was originally developed and tested for content and construct validity and for homogeneity and reliability in a Swedish setting. The validity, as well as the reliability, properties were considered sufficient [16].

Respondents list their answer as "yes/no" or "no opinion", "agree/don't agree", "true/false", or "don't know". The *experiences* domain includes items about patients' actual discussion experiences. Example items in the *experiences* domain are "I have discussed what a battery replacement involves with my ICD doctor or nurse", and "I have told my next of kin (either in writing or orally) my wishes regarding the defibrillator shocks in my ICD, if I become seriously ill with some fatal disease". The *attitudes* domain includes items about patients' attitudes towards potential future discussions and future events. Examples of items on the *attitudes* domain are "I do not wish to have a conversation about turning off defibrillating shocks with my doctor", "I want to have the battery in my ICD replaced even if I am seriously ill suffering from another disease", and "I want to have the defibrillating shocks in my ICD even if dying of cancer or another serious disease". The *knowledge* domain involves questions such as "Turning off the defibrillating shocks in an ICD is the same as active euthanasia", and "An ICD always gives defibrillating shocks in connection with end-of-life". In this paper we are reporting results from the *experiences* and *attitudes* domains only.

2.2.3. Psychological measures and quality-of-life

Given the possibility that psychological distress might influence patients' experiences and attitudes toward end-of-life concerns, questionnaires assessing QOL, anxiety symptoms, and depressive symptoms were also included in the survey. Quality-of-life was measured using the EuroQol-5D [17], an instrument with well-established reliability and validity. Anxiety and depression symptoms were assessed using the 8-item Hospital Anxiety and Depression Scale (HADS) [18], which has been used extensively in the evaluation of anxiety and depression symptoms in both hospitalized and non-hospitalized patients.

2.3. Statistical analysis

Data were analyzed with SPSS software, version 21.0 (SPSS, Chicago, Illinois). Probability values of $p < .05$ were considered significant. Comparisons between study participants and non-participants on background characteristics were performed using the Chi-square test for nominal variables (e.g., gender, ICD indication) and two-tailed Student's *t*-test for independent samples for continuous variables (e.g., age, time since implantation). Simple frequencies and proportions were used to describe the patient sample, frequency and timing of occurrence of discussions about ICD deactivation, and attitudes about battery replacement and deactivation.

A series of logistic regression models was used to determine the association of sociodemographic and clinical variables (i.e., gender, age, education, ICD indication, time since implantation, type of ICD (CRT-D versus ICD), shock experience, and prior ICD battery replacement) controlling for anxiety symptoms, depressive symptoms and QOL, with patient's experiences of, and attitudes towards, end-of-life discussions and withdrawal of therapy at end-of-life. In these models we determined predictors of a "yes" or "no" answer to each question about experiences of end-of-life discussions, and attitudes towards end-of-life discussions and withdrawal of therapy at the end-of-life. Each of the predictor variables were forced into the model in order to provide simultaneous control for all variables.

Chi-square tests were used to determine bivariate association of socio-demographic, clinical, and psychological measures with (1) attitudes on elective generator replacement at end-of-service indicator; (2) attitudes on deactivation at end-of-life, and (3) attitudes about maintaining ICD therapy in the context of terminal illness. For the Chi-square tests, post-hoc examination of the standardized residuals that exceeded the critical value associated with $p < .05$ was used to determine which cell or cells contributed to the significant difference.

Multinomial logistic regression was used to determine predictors of the response to the item asking for patients' attitudes regarding the item, "I want to have the defibrillating shocks in my ICD even if dying of cancer or other serious disease". Because this item has three potential responses (i.e., yes, no, or can't take a stand), multinomial versus logistic regression was used.

Finally, given the finding that a large percentage of respondents were indecisive with regard to ability to make a decision about withdrawal of therapy and deactivation under specific circumstances, we conducted an additional analysis using linear regression to determine predictors of indecisiveness. The dependent variable was created by averaging scores of five items from the attitude domain. These items focused on ability to come to a decision about battery replacement under the circumstances of having not received shocks, being seriously ill and having reached an advanced age, plus two questions about choosing to keep the ICD active even if dying from cancer or other serious illness, or if receiving shocks daily. Predictors included in the regression analysis involved background characteristics, clinical characteristics, and psychological measures. Predictors were forced into the model to provide simultaneous control of all variables.

3. Results

Of the 5535 patients approached, 1502 did not respond, 700 patients declined to participate, 96 chose to withdraw from the study, and 170 did not return the questionnaire despite one reminder. A total of 3067 patients completed the survey (55% response rate). No statistically significant differences were found in background characteristics in terms of age, gender, time since implantation, or ICD indication between participants and non-participants.

3.1. Background Characteristics

Sample characteristics are presented in Table 1. The mean age of the sample was 66 years with a range of ages enrolled from 19 to 94 years, and 80% were male. Time since implantation ranged from one to 23 years with a mean of 4.7 years, 23% had a CRT-D implanted and 25% had previously undergone an elective battery replacement. The majority (64%) had received their ICD as a secondary prevention treatment, while the remainder had received their ICD for primary prevention, usually in the context of heart failure.

The vast majority (96%) of patients rated their general experience as an ICD recipient as "very", or "rather good" compared to only 4% who rated it "rather" or "very bad". Sixteen percent of patients stated that they had religious faith or a religious outlook on life that helped them manage life as an ICD recipient. A total of 35% of patients had experienced one or more defibrillating shocks. In connection with the latest

shock, the pain as well as the anxiety experience was considered mild (4.6 and 4.5, respectively), when rated on a visual analog scale (where 0 means no pain/anxiety and 10 the worst possible pain/anxiety imaginable). Of the sample, only 4% had, at some point, considered deactivation of their ICD.

3.2. Experiences and Attitudes toward Withdrawal-of-Therapy-Discussions

Only 43% of patients had at some time discussed what a forthcoming battery replacement would involve with their physician, and 32% had discussed the topic with a family member. Among the predictors entered into the model, QoL, age, time since implantation, and prior battery replacement independently predicted whether patients had had such a discussion (Table 2). Patients with better QoL, those younger than 65, those who had the ICD implanted for a longer period of time, and those who had a prior battery replacement were more likely to have discussed battery replacement with their clinician. With regard to predictors of having such a discussion with their family members, again, patients with better QoL, those younger than 65, those with the ICD for a longer period of time, and those who had a prior battery replacement were more likely to have discussed battery replacement with their next-of-kin (Table 2).

The vast majority (86%) had not had a discussion with their clinician about what ICD deactivation and turning off defibrillating shocks would involve. Logistic regression demonstrated that anxious patients, younger patients, and those who had received ICD shocks and prior battery replacement were more likely to have had such a discussion (Table 2). Just one-tenth of patients had discussed the implications of ICD deactivation with their family members. Independent predictors of this discussion with family members were presence of anxiety symptoms, having received prior defibrillating shocks or prior battery replacement (Table 2). Only 7% had told their family members of their wishes for ICD deactivation if they become seriously ill with a fatal disease. Only female gender or prior battery replacement were independent predictors of having this discussion (Table 2). A minority (37%) stated they had discussed with their physician their underlying illness and what to expect for the illness trajectory in the future. Variables that independently predicted engagement in such a discussion were male gender, age younger than 65, history of defibrillating shocks, higher levels of education, and having an ICD versus a CRT-D implanted (Table 2). A similar minority (37%) had discussed their heart disease and its progression with their family members. Independent predictors of having such a discussion were age younger than 65, history of defibrillating shocks, higher levels of education, and having an ICD versus a CRT-D implanted (Table 2).

Table 1
Demographic and clinical characteristics, N = 3067.

Characteristic		Value [a]
Demographics		
Age (years)	65.9	(11.5)
Gender (male)	2438	(79.5%)
Education (lower) [b]	1009	(33.2%)
Clinical factors		
Time since implantation (years)	4.7	(3.9)
ICD-indication (primary prevention)	1109	(36.2%)
Resynchronization therapy (CRT-D, yes)	717	(23.4%)
Shock experience (yes)	1056	(34.9%)
Generator replacement (yes)	774	(25.2%)
Co-morbidity [c]		
Myocardial infarction	1037	(33.8%)
Atrial fibrillation	1280	(41.8%)
Heart failure	1606	(52.4%)
Chronic obstructive pulmonary disease	448	(14.6%)
Diabetes mellitus	612	(20.0%)
Stroke	272	(8.9%)
Cancer	202	(6.6%)
Psychological measures [d]		
Quality-of-life index, mean	.818	(.211)
Quality-of-life, visual analog scale	72.8	(18.2)
Anxiety	485	(16.1%)
Depression	263	(8.7%)

[a] Data are presented as mean ± SD or n (%).
[b] Compulsory secondary school, with a total education time < 9 years.
[c] Self-reported by subjects.
[d] Psychological measures: QOL was assessed with EQ-5D (mean index score and visual analog score-VAS; a higher score indicated a better QOL), anxiety and depression with HADS (categorical with a cut-offs ≥8 indicating anxiety/depression).

3.3. Timing of Discussions about ICD Deactivation

With regard to attitudes about discussion surrounding ICD deactivation in an anticipated end-of-life situation, 40% of patients stated that they never wanted the physician to initiate a discussion, while 84% stated they wanted to broach the question about deactivation when they felt it was needed. Most patients (69%) stated that they preferred discussing what is involved with ICD deactivation during the last days in life, yet 50% also said they would like the discussion to be held in connection with the ICD implantation. Overall, most people would prefer these discussions be held when their health deteriorates, rather than routinely (Table 3).

We determined predictors of the attitude of never wanting the physician to discuss ICD deactivation. Based on logistic regression, the patients who did not want to discuss ICD deactivation were more likely to be younger and without symptoms of anxiety. In addition, these patients were more likely to have received prior ICD shocks (Table 4).

3.4. Attitudes toward Withdrawal of Therapy at the Battery-End-of-Service

The majority of patients stated that even if no shock therapy had been delivered (79%) they would like to replace the ICD battery when it has reached the end-of-service indicator, while 16% could not take a stand on this item, and 5% would not want to replace the ICD battery in this circumstance. The prevalence of these attitudes by various sociodemographic, implantation, psychological and end-of-life discussion experiences are indicated in Table 5. From bivariate analyses, there were no differences in the prevalence of these attitudes based on gender, whether the ICD was inserted for primary or secondary prevention, type of ICD (i.e., CRT-D or ICD), receipt of prior shocks, symptoms of anxiety, or prior discussions with the ICD team about deactivation. There were significant differences based on age, education, time since ICD implantation, prior battery replacement, having had discussions with the ICD team about battery replacement and about illness trajectory. Specifically, patients who were younger, those with lower levels of education, and those with depressive symptoms were more likely to state that they did not want the battery replaced even if no shocks had been delivered. Significantly more patients who had their ICD for 5 or fewer years were unable to take a stand than those who had their ICD for longer than 5 years. Patients who had a prior battery replacement were less likely to state they could not take a stand regarding battery replacement if no shocks had been delivered. Patients who had any prior discussion with the ICD team about battery replacement were less likely to be unable to take a stand as were those who had a prior discussion about illness trajectory.

The majority of patients also reported wanting to replace the battery even when they reached a very advanced age (63%), while 27% could not take a stand, and 10% did not want the battery replaced in this circumstance. The prevalence of these attitudes by various sociodemographic, implantation, psychological and end-of-life discussion experiences are indicated in Table 6. Younger patients more commonly said they did not want the battery replaced even at an advanced age, and men more commonly said they did want it replaced than did women, although women more commonly than men were unable to take a stand. Those who had no prior discussion about battery

Table 2
Logistic regression results for experiences of, and attitudes towards, withdrawal-of-ICD-therapy-discussions, N = 3067.

	B	P value	Odds ratio	95% CI
Discussed what battery replacement involves with ICD physician or nurse, Omnibus p value < .001				
Symptoms of depression	−.311	.086	.733	.513–1.046
Symptoms of anxiety	.086	.534	1.089	.832–1.427
Quality-of-life score	.480	.045	1.615	1.010–2.584
Male	.071	.511	1.074	.869–1.327
Age < 65 years (vs. ≥65 years)	.299	<.001	1.349	1.123–1.620
≤9 years of education (vs. >9 years)	−.086	.361	.918	.764–1.103
Time since implantation of ICD, years	.122	<.001	1.130	1.090–1.173
CRT-D (vs. ICD only)	.065	.547	1.067	.864–1.317
Secondary prevention (vs. primary)	.129	.187	1.137	.939–1.377
Received ICD shocks	.055	.567	1.057	.874–1.278
Had prior generator replacement	1.558	<.001	4.739	3.565–6.298
Discussed what battery replacement involves with family, Omnibus p value < .001				
Symptoms of depression	−.248	.183	.781	.543–1.123
Symptoms of anxiety	.125	.375	1.133	.860–1.492
Quality-of-life score	.511	.039	1.667	1.027–2.707
Male	.179	.098	1.196	.968–1.477
Age < 65 years (vs. ≥65 years)	.325	.001	1.384	1.149–1.667
≤ 9 years of education (vs. >9 years)	.026	.787	1.026	.850–1.239
Time since implantation of ICD, years	.110	<.001	1.117	1.080–1.155
CRT-D (vs. ICD only)	.151	.172	1.163	.936–1.445
Secondary prevention (vs. primary)	.152	.140	1.165	.951–1.426
Received ICD shocks	−.060	.545	.942	.776–1.143
Had prior generator replacement	1.169	<.001	3.219	2.479–4.180
Discussed with ICD physician or nurse what turning off defibrillating shocks involves, Omnibus p value < .001				
Symptoms of depression	−.079	.708	.924	.613–1.393
Symptoms of anxiety	.494	.002	1.638	1.198–2.239
Quality-of-life score	−.186	.518	.830	.472–1.460
Male	−.034	.804	.967	.741–1.262
Age < 65 years (vs. ≥65 years)	.311	.008	1.364	1.084–1.717
≤9 years of education (vs. >9 years)	.123	.306	1.131	.894–1.430
Time since implantation of ICD, years	.014	.476	1.014	.976–1.052
CRT-D (vs. ICD only)	.014	.922	1.014	.770–1.335
Secondary prevention (vs. primary)	−.042	.752	.959	.739–1.244
Received ICD shocks	.585	<.001	1.795	1.422–2.265
Had prior generator replacement	.735	<.000	2.086	1.504–2.893
Discussed with family what turning off defibrillating shocks involves, Omnibus p value < .001				
Symptoms of depression	.013	.955	1.013	.654–1.569
Symptoms of anxiety	.582	.001	1.789	1.279–2.503
Quality-of-life score	−.294	.342	.746	.407–1.366
Male	.201	.167	1.223	.920–1.626
Age < 65 years (vs. ≥65 years)	.142	.281	1.152	.890–1.491
≤9 years of education (vs. >9 years)	.152	.250	1.165	.899–1.509
Time since implantation of ICD, years	.017	.417	1.017	.976–1.061
CRT-D (vs. ICD only)	−.105	.508	.900	.660–1.229
Secondary prevention (vs. primary)	−.059	.689	.943	.706–1.258
Received ICD shocks	.511	< .001	1.667	1.285–2.163
Had prior generator replacement	.505	.007	1.658	1.147–2.396
Discussed with family wishes if seriously ill with fatal disease, Omnibus p value < .001				
Symptoms of depression	.068	.808	1.070	.621–1.842
Symptoms of anxiety	.139	.531	1.149	.744–1.773
Quality-of-life score	−.683	.058	.505	.249–1.024
Male	.359	.036	1.432	1.024–2.003
Age < 65 years (vs. ≥65 years)	.114	.479	1.121	.818–1.536
≤9 years of education (vs. >9 years)	.069	.672	1.071	.779–1.475
Time since implantation of ICD, years	−.009	.750	.991	.941–1.045
CRT-D (vs. ICD only)	.106	.564	1.112	.776–1.592
Secondary prevention (vs. primary)	−.142	.422	.867	.613–1.227
Received ICD shocks	.158	.341	1.171	.846–1.622
Had prior generator replacement	.705	.002	2.023	1.288–3.179
Discussed illness trajectory with ICD physician or nurse, Omnibus p value < .001				
Symptoms of depression	−.221	.183	.802	.579–1.110
Symptoms of anxiety	.055	.666	1.057	.823–1.357
Quality-of-life score	−.272	.209	.762	.499–1.165
Male	−.377	<.001	.686	.561–.838
Age < 65 years (vs. ≥65 years)	.461	<.001	1.585	1.340–1.876
≤9 years of education (vs. >9 years)	−.443	<.001	.642	.539–.764
Time since implantation of ICD, years	.011	.458	1.012	.981–1.043
CRT-D (vs. ICD only)	.387	<.001	1.472	1.212–1.787
Secondary prevention (vs. primary)	−.080	.386	.923	.770–1.107
Received ICD shocks	.465	<.001	1.592	1.337–1.896

(continued on next page)

Table 2 (*continued*)

	B	P value	Odds ratio	95% CI
Had prior generator replacement	.259	.052	1.295	.997–1.682
Discussed heart disease development with family, Omnibus p value < .001				
Symptoms of depression	.065	.686	1.067	.779–1.460
Symptoms of anxiety	.068	.587	1.070	.837–1.368
Quality-of-life score	−.203	.341	.816	.538–1.239
Male	−.039	.690	.962	.793–1.166
Age < 65 years (vs. ≥65 years)	.359	<.001	1.432	1.213–1.690
≤9 years of education (vs. >9 years)	−.296	.001	.743	.627–.882
Time since implantation of ICD, years	.004	.777	1.004	.975–1.035
CRT-D (vs. ICD only)	.347	<.001	1.415	1.170–1.712
Secondary prevention (vs. primary)	−.171	.059	.843	.705–1.007
Received ICD shocks	.255	.004	1.291	1.085–1.535
Had prior generator replacement	.169	.202	1.284	.913–1.534

Legend: CI = Confidence Intervals; CRT-D = Cardiac Resynchronization Therapy-Defibrillator; ICD = Implantable Cardioverter Defibrillator.

replacement more commonly were unable to take a stand on this issue, while those who had a prior discussion more commonly said they wanted battery replacement even at an advanced age. There were no differences in attitudes based on education level, ICD indication, ICD type, time since implantation, prior shock experience, prior generator replacement, presence of symptoms of anxiety or depression, or prior discussions about illness trajectory or ICD deactivation.

A majority of patients (55%) desired battery replacement even if seriously ill, while 34% were unable to take a stand on this issue, and 11% said no. The prevalence of these attitudes by various socio-demographic, implantation, psychological and end-of-life discussion experiences are indicated in Table 7. Women either more commonly said they could not take a stand or said no to this issue, those with a CRT-D less commonly said no, and those who had discussed deactivation with their ICD team more commonly said no. There were no differences in attitudes based on age, education level, ICD indication, time since implantation, prior shock experience, prior generator replacement, presence of symptoms of anxiety or depression, or prior discussions about illness trajectory or battery replacement.

3.5. Attitudes toward ICD Deactivation at End-of-Life

More patients "could not take a stand (39%) about whether they would like to have the ICD deactivated if a terminal illness developed" than said "yes (22%), they would like it deactivated" or "no (39%), they do not want it deactivated even if a terminal illness like cancer developed". There were no differences in the prevalence of these attitudes based on age, education level, ICD indication, time since implantation, receipt of previous shocks, symptoms of anxiety, depressive symptoms, having had a prior discussion with the physician about battery replacement, or having had a prior discussion with the physician about illness trajectory (Table 8). There were differences based on gender, type of ICD, prior battery replacement, and prior discussions with the physician about deactivation. Specifically, women were less likely to say "yes, they would like to have the ICD deactivated if a terminal illness developed", as were those with prior battery replacement. Those with a CRT-D were more likely to say "yes", and those who had a prior discussion with their physician about deactivation were less likely to say they often "could not take a stand" (Table 8). Multinomial logistic regression revealed that only gender, having had a prior discussion about ICD deactivation with the physician, and CRT-D therapy predicted this attitude. Compared to patients who stated "no" to the item asking if they would like to have the ICD deactivated if a terminal illness developed, those who said "yes" were more likely to be men (Odds ratio 1.79, 95% confidence intervals (CI) 1.36–2.34, $p < .001$) and more likely to have a CRT-D versus ICD implanted (Odds ratio 1.35, 95% CI 1.06–1.73, $p = .017$). No other covariates entered into the model.

3.6. Predictors of indecisiveness

Given our unexpected findings of a large number of patients who were indecisive (i.e., unable to take a stand) about a number of end-of-life issues related to their ICD, we conducted a secondary analysis to further explore this phenomenon. We used linear regression in order to determine predictors of indecisiveness from the following variables: gender; age; education level; type of ICD; ICD indication; time since implantation; history of myocardial infarction, heart failure or cancer; quality-of-life score; depressive symptoms; anxiety symptoms; prior discussions with the ICD team about battery replacement and ICD deactivation; general experiences with the ICD; prior ICD shocks; anxiety related to ICD shocks; and pain related to ICD shocks. The overall

Table 3
Attitudes about preferable situations in which to discuss what ICD deactivation involves, N = 3067.

Specific situation	Value [a]
I don't wish to have such a conversation	1204 (40.0)
I myself will broach the question when I feel the need to	2529 (84.3)
In connection with the ICD surgery	1466 (49.6)
If I receive a shock	1502 (50.5)
If I have repeated shocks	1938 (65.2)
Upon repeatedly being hospitalized due to recurring heart problems	1870 (63.0)
If I should suffer from a disease with a poor prognosis (e.g., cancer)	1932 (64.6)
Routinely upon return visits to the ICD clinic	1249 (41.7)
If my heart disease, which is the reason for the ICD treatment, deteriorates	1935 (64.8)
Towards end-of-life, during the last days	2043 (69.1)

[a] Data are presented as number and percentages, with proportions of patients agreeing to each statement. Patients were asked to take a stand for each statement.

Table 4
Logistic regression for attitude about when the patient would like clinicians to broach the subject of what is involved when turning of the defibrillating shocks, N = 3067.

Never wishes to have such a discussion, Omnibus p value < .001	B	P value	Odds ratio	95% CI
Symptoms of depression	−.031	.850	.969	.701–1.340
Symptoms of anxiety	−.435	.001	.647	.501–.835
Quality-of-life score	.207	.342	1.230	.803–1.884
Male	−.098	.315	.906	.748–1.098
Age < 65 years (vs. ≥65 years)	.230	.006	1.259	1.067–1.486
≤9 years of education (vs. >9 years)	−.074	.385	.929	.786–1.097
Time since implantation of ICD, years	.002	.870	1.002	.973–1.033
CRT-D (vs. ICD only)	−.069	.481	.933	.770–1.131
Secondary prevention (vs. primary)	−.036	.692	.965	.808–1.151
Received ICD shocks	.422	<.001	1.525	1.285–1.810
Had prior generator replacement	.154	.239	1.166	.903–1.506

Legend: CI = confidence intervals; CRT-D = Cardiac Resynchronization Therapy-Defibrillator; ICD = Implantable Cardioverter Defibrillator.

Table 5
Prevalence of attitudes regarding ICD battery replacement even if no shocks have been delivered N = 3067 *.

Socio-demographics	Age**		Sex		Education level **	
	<65 years N (%)	≥65 years N (%)	Male N (%)	Female N (%)	≤9 years N (%)	>9 years N (%)
Yes	861 (81.8)	1520 (78.3)	1893 (79.6)	488 (79.1)	749 (77.0)	1613 (80.7)
No	33 (3.1) ***	108 (5.5)	114 (4.8)	27 (4.4)	62 (6.4) ***	78 (3.9)
Can't take a stand	159 (15.1)	314 (16.2)	371 (15.6)	102 (16.5)	161 (16.6)	308 (15.4)

Implantation indication and device	ICD indication		CRT	
	Primary	Secondary	Yes	No
Yes	858 (79.6)	1522 (79.4)	556 (80.1)	1821 (79.3)
No	40 (3.7)	101 (5.3)	26 (3.8)	115 (5.0)
Can't take a stand	180 (16.7)	293 (15.3)	112 (16.1)	361 (15.7)

Post-implantation experiences	Time since implant **		Shock experience		Generator replacement **	
	≤5 years	>5 years	Shock	No shock	Yes	No
Yes	1639 (77.7)	742 (83.8)	814 (79.0)	1546 (80.1)	633 (83.5)	1748 (78.1)
No	100 (4.7)	41 (4.7)	56 (5.4)	82 (4.2)	41 (5.4)	100 (4.5)
Can't take a stand	371 (17.6) ***	102 (11.5) ***	161 (15.6)	302 (15.7)	84 (11.1) ***	389 (17.4) ***

Psychological factors	Symptoms of anxiety		Symptoms of depression**	
	Yes	No	Yes	No
Yes	362 (76.7)	1982 (80.2)	187 (73.6)	2158 (80.1)
No	24 (5.1)	116 (4.7)	21 (8.3) ***	118 (4.4)
Can't take a stand	86 (18.2)	374 (15.1)	46 (18.1)	419 (15.5)

End-of-life discussions with ICD team	Battery replacement **		Illness trajectory **		Deactivation	
	Yes	No	Yes	No	Yes	No
Yes	1080 (83.9)	1283 (76.2)	909 (82.0)	1445 (78.0)	337 (78.7)	2023 (79.7)
No	62 (4.8)	77 (4.6)	50 (4.5)	89 (4.8)	26 (6.1)	111 (4.4)
Can't take a stand	145 (11.3) ***	324 (19.2) ***	149 (13.5) ***	318 (17.2)	65 (15.2)	404 (15.9)

Legend: * Of the total, yes, n = 2381 (79.5%); no, n = 141 (4.7%); can't take a stand, n = 473 (15.4%); ** = overall chi-square significant at $p < .05$; *** = post-hoc examination of the standardized residuals was used to determine which cell or cells contributed to the significant difference and those cells marked with a *** exceeded the critical value associated with $p < .05$.

model was significant ($p = .001$), and of the variables entered, only gender (β.108, $p = .001$), depressive symptoms (β.122, $p = .002$), and experiences with the ICD (β. 077, $p = .036$) were significant predictors. Women, those without depressive symptoms, and those with worse ICD experiences were more indecisive.

4. Discussion

In our nationwide survey of more than 3000 patients with ICDs, we found that only a minority had discussed the implications of generator replacement at battery-end-of-service or had discussed potential ICD deactivation at the end-of-life. Moreover, many patients were unable to foresee what they might prefer to do with their ICD in an end-of-life situation. These findings suggest a number of possibilities with regard to the recommendations offered in current expert consensus statements about managing ICD patients [1,2], the effectiveness of such statements, and whether they are being followed.

As Kramer and colleagues [19] recently discussed; is it time for a new approach to ICD replacements? They point to the fact that the appropriateness of initial device placement has been closely scrutinized, but there has been little consideration as to what happens in the years after implantation when ICD battery drains sufficiently to require replacement. They suggest that the guidelines for initial ICD implantation [20] should be followed when making recommendations to patients regarding replacement, i.e., the patient should be expected to survive for at least one year with a reasonable quality-of-life. When we asked our participants, however, the majority stated that they would like to replace the battery, even if no shock therapy had been delivered, even if they had reached a very advanced age, or even if they were seriously ill with a terminal disease like cancer. This implies the importance of making battery replacement a more deliberative process where patient preferences, past experiences, and advance care planning should be explicitly included in decision making together with a comprehensive medical evaluation [19].

We found a strikingly low rate of discussions about the possibility of deactivating the device near the end-of-life suggesting a lack of concordance with the current consensus statements. Before implanting an ICD, clinicians should explain that these devices may avert sudden cardiac death, but that later in life the benefits versus the negatives of the ICDs should be re-evaluated. For example, if the patient is stricken with a fatal illness, the physician should, in accordance with existing expert consensus statements [1,2], explain that death from an arrhythmia may be a better mode of dying than that the patient faces from their terminal condition. The statements also suggest that the physician should explain that repeated ICD shocks may be distressing to the patient and family as death nears. However – and in contrast to the advice given by experts in the consensus statements [1,2] – as many as 40% of our participants stated that they never wanted the physician to initiate a discussion about deactivation in an anticipated end-of-life situation and those in favor of a discussion, preferred it to take place during the last days in life. Others have also reported that patients prefer to discuss deactivation only late in their illness trajectory [6,7]. This highlights the importance that the opinion of patients should be considered at the time of initiating a discussion on terminal conditions or delivery these types of documents. When attempting to define sub-groups of patients who had participated in discussions about withdrawal of ICD therapy, we found that anxious patients, patients younger than 65 years, and those who had received ICD shocks and prior battery replacement were more likely to have had such a discussion. These findings could be explained by the fact that relative youth may be associated with a

Table 6
Prevalence of attitudes regarding ICD battery replacement even if at an advanced age, N = 3067*.

Socio-demographics	Age **		Sex **		Education level	
	<65 years N (%)	≥65 years N (%)	Male N (%)	Female N (%)	≤9 years N (%)	>9 years N (%)
Yes	609 (57.9)	1267 (65.1)	1571 (66.1)***	305 (49.3) ***	620 (63.3)	1240 (62.3)
No	131 (12.5) ***	174 (8.9)	207 (8.7) ***	98 (15.8) ***	108 (11.0)	196 (9.8)
Can't take a stand	311 (29.6)	504 (25.9)	599 (25.2)	216 (34.9) ***	252 (25.7)	555 (27.9)

Implantation indication and device	ICD indication		CRT **	
	Primary	Secondary	Yes	No
Yes	670 (62.2)	1205 (62.8)	459 (65.8)	1414 (61.6)
No	108 (10.0)	197 (10.3)	55 (7.9)	250 (10.9)
Can't take a stand	300 (27.8)	515 (26.9)	183 (26.3)	631 (27.5)

Post-implantation experiences	Time since implant		Shock experience **		Generator replacement	
	≤5 years	>5 years	Shock	No shock	Yes	No
Yes	1308 (62.0)	568 (64.2)	685 (66.3)	1175 (60.9)	477 (62.9)	1399 (62.5)
No	210 (9.9)	95 (10.7)	95 (9.2)	204 (10.6)	89 (11.7)	216 (9.7)
Can't take a stand	593 (28.1)	222 (25.1)	253 (24.5)	549 (28.5)	192 (25.4)	623 (27.8)

Psychological factors	Symptoms of anxiety		Symptoms of depression	
	Yes	No	Yes	No
Yes	276 (58.9)	1568 (63.3)	148 (58.3)	1698 (63.0)
No	56 (11.9)	243 (9.8)	34 (13.4)	265 (9.8)
Can't take a stand	137 (29.2)	665 (26.9)	72 (28.3)	734 (27.2)

End of life discussions with ICD team	Battery replacement ***		Illness trajectory		Deactivation	
	Yes	No	Yes	No	Yes	No
Yes	865 (67.3) ***	999 (59.3)	723 (65.3)	1135 (61.1)	282 (66.0)	1578 (62.1)
No	121 (9.4)	179 (10.6)	110 (9.9)	191 (10.3)	49 (11.5)	252 (9.9)
Can't take a stand	299 (23.3) ***	508 (30.1) ***	274 (24.8)	530 (28.6)	96 (22.5)	712 (28.0)

Legend: * Of the total, yes, n = 1876 (62.6%); no, n = 305 (10.2%); can't take a stand, n = 815 (27.2%); ** = overall chi-square significant at $p < .05$; *** = post-hoc examination of the standardized residuals was used to determine which cell or cells contributed to the significant difference and those cells marked with a *** exceeded the critical value associated with $p < .05$.

more proactive way of communicating with healthcare professionals and the experience of having an arrhythmia that results in ICD shocks leads to more consultations and thus more opportunities to have this conversation. Anxiety is a common factor in promoting discussions as anxious patients attempt to resolve their anxiety by gaining more information.

We also found that the majority of the participants had not discussed their illness trajectory with their physician or a family member. While advanced directives are considered an essential part of care for the ICD population, this was not a reality in our study where only 7% had expressed their preferable wishes, verbally or in writing, to their family. This is in line with Conelius [13] who found that participants were uncomfortable discussing advanced directives with their families. It is reasonable to assume that these preferences emanate from a wish to postpone decisions and even forget about the real reason for having an ICD. This desire by patients to avoid such discussions is in conflict with existing consensus statements [1,2] that recommend discussions of deactivation when the patient's clinical status worsens. Statements are based on the knowledge that ICD shocks are painful and psychologically stressful as well as futile in terminal illness. Expert recommendations, however, assume that patients are willing and prepared to have a discussion about their illness and end-of-life issues while in reality, most are not and most could not foresee if they would prefer to withdraw ICD therapy even if dying from a terminal illness. Our findings suggest that clinicians may need to concentrate on better preparing patients to have discussions about the end-of-life and this need should be acknowledged in future guidelines. It also may be that clinicians need further education about how to appropriately engage in end-of-life discussions with ICD patients [21]. These factors are important because ICD patients and their families cannot make appropriate decisions without a clear understanding of available options, which may lead to a prolonged and uncomfortable death [22].

Although a large number of our patients could not take a stand about ICD deactivation if confronted with a terminal illness, of those who could take a stand in advance, the majority stated that they would prefer deactivation. Every fifth patient, however, believed that they would like the shock therapies to remain active. These results support findings from previous, small scale studies demonstrating that the majority of patients prefer to keep their ICD active [5,7,10] while some favor device deactivation at end-of-life [6,9]. Together these data demonstrate that ICD recipients form a heterogeneous group.

What clinical conclusions can be drawn from these results? One of the most striking finding in our study is the unwillingness in certain groups to have a discussion about deactivation. This, however, cannot be taken as a pretext for failing to provide patients with their options in an end-of-life situation. Rather this finding highlights the importance of being aware of patients' ambivalence, understanding that preferences are unique among individuals, and that patients with different characteristics have different needs. Thus, the timing of every discussion with the patient must be decided on an individual basis. This is particularly important because illness trajectory and terminal deterioration of health often is unpredictable [23–27]. However, continuity of care for patients with an ICD in the end-of-life is complex [28]. One reason for this is the lack of collaboration among healthcare providers which may lead to fragmented care for the ICD patient [22] and this should also be acknowledged in future guidelines.

Because previous research [29] has suggested that patients may be too anxious when diagnosed and thus are not receptive to having

Table 7
Prevalence of attitudes regarding ICD battery replacement even if seriously ill with another disease, N = 3067 *.

Socio-demographics	Age		Sex **		Education level	
	<65 years N (%)	≥65 years N (%)	Male N (%)	Female N (%)	≤9 years N (%)	>9 years N (%)
Yes	564 (53.7)	1070 (55.1)	1354 (57.0)	280 (45.3) ***	542 (55.5)	1079 (54.1)
No	123 (11.7)	206 (10.6)	240 (10.1)	89 (14.4) ***	120 (12.3)	208 (10.5)
Can't take a stand	364 (34.6)	667 (34.3)	782 (32.9)	249 (40.3) ***	315 (32.2)	706 (35.4)

Implantation indication and device	ICD indication		CRT**	
	Primary	Secondary	Yes	No
Yes	574 (53.4)	1060 (55.3)	400 (57.5)	1231 (53.7)
No	122 (11.3)	207 (10.8)	59 (8.5) ***	270 (11.8)
Can't take a stand	380 (35.3)	650 (33.9)	237 (34.0)	793 (34.5)

Post-implantation experiences	Time since implant		Shock experience		Generator replacement	
	≤5 years	>5 years	Shock	No shock	Yes	No
Yes	1128 (53.4)	506 (57.3)	584 (56.7)	1031 (53.4)	420 (55.6)	1214 (54.2)
No	227 (10.8)	102 (11.6)	123 (11.9)	200 (10.4)	88 (11.6)	241 (10.8)
Can't take a stand	756 (35.8)	275 (31.1)	323 (31.4)	698 (36.2)	248 (32.8)	783 (35.0)

Psychological factors	Symptoms of anxiety		Symptoms of depression	
	Yes	No	Yes	No
Yes	247 (52.3)	1357 (54.9)	134 (52.7)	1475 (54.8)
No	56 (11.9)	270 (10.9)	37 (14.6)	283 (10.5)
Can't take a stand	169 (35.8)	845 (34.2)	83 (32.7)	935 (34.7)

End of life discussions with ICD team	Battery replacement		Illness trajectory **		Deactivation	
	Yes	No	Yes	No	Yes	No
Yes	748 (58.3)	874 (51.8)	639 (57.7)	977 (52.7)	234 (54.8)	1384 (54.5)
No	133 (10.4)	193 (11.4)	108 (9.8) ***	216 (11.6)	63 (14.8)	261 (10.3)
Can't take a stand	401 (31.3)	621 (36.8)	360 (32.5)	661 (35.7)	130 (30.4)	895 (35.2)

Legend: * Of the total, yes, n = 1634 (54.6%); no, n = 329 (11%); can't take a stand, n = 1031 (34.4%); ** = overall chi-square significant at $p < .05$; *** = post-hoc examination of the standardized residuals was used to determine which cell or cells contributed to the significant difference and those cells marked with a *** exceeded the critical value associated with $p < .05$.

such discussions at that stage, perhaps end-of-life issues should be discussed at follow-up visits but not pre-implantation as suggested in expert consensus statements [1,2]. Further supporting this suggestion is the finding that many patients change their minds regarding deactivation over the course of their illness [29]. Half of our participants, however, favored receiving information about deactivation while in the hospital. Together this and related data suggest that frequent attempts at discussion starting from the first consultation prior to implantation – as suggested in consensus statements – and continuing on through the post-implantation period and as patients' conditions change, seem reasonable and is also in line with Dunbar and colleagues' recommendations about educational and psychological interventions to improve ICD recipient outcomes [21]. When such discussions are done with sensitivity to patient preferences, they likely will not be viewed as offensive, but presumed to be in every patient's best interest.

It is also possible that resistance to discussing deactivation partly can be explained by lack of actual knowledge and true understanding of the ICD and its functions. Many patients do not understand the specifics of their device with regard to their medical condition [13,30,31]. By openly discussing the illness trajectory and option of deactivating an ICD, after providing patients with sufficient knowledge to process these discussions, clinicians encourage shared decision making and provide patients control over their healthcare choices. A better understanding of patients' actual insights in their disease and the role of the ICD could be reached with the help of specific questionnaires in addition to discussions throughout the illness trajectory and make it possible to design an individual scheme for education and support. This way to optimize follow-up and patient support has to be further investigated, however.

4.1. Limitations

This study is limited by the fact that the most psychologically distressed patients and those with poor physical and mental functioning may not have agreed to participate. Although there were no differences in age, gender, time since implantation and indication for the ICD between those who participated in the study and those who did not, we were unable to collect further data from those who did not participate. Furthermore, persons responding may want to be perceived as "good patients" by not reporting problems, although our consent process insured that patients were informed that the questionnaires would be made anonymous before data entry. Only one data collection point was used, and longitudinal study of a cohort of patients would be helpful in understanding the process of adjustment, experiences, and attitudes and knowledge about the ICD over time. Further, more than 60% of patients had ICD implanted as secondary prevention. This is a relatively high rate for current practice which could be seen as a limitation. Lastly, this was an observational study and thus we can only report association rather than infer causation.

5. Conclusions

In this study, we examined experiences of discussion, and attitudes about end-of-life among patients with an ICD while controlling for levels of psychological distress and quality-of-life. The vast majority of the patients had not discussed deactivation with the ICD team and a large minority of younger and healthier patients did not want this discussion at all. Many patients, above all women, those with recent implant and those with good quality-of-life or those with worse ICD

Table 8
Prevalence of attitudes regarding the maintenance of ICD therapy in the context of terminal illness (keep shocks even if dying of cancer or other serious disease), N = 3067 *.

Socio-demographics	Age		Sex **		Education level	
	<65 years N (%)	≥65 years N (%)	Male N (%)	Female N (%)	≤9 years N (%)	>9 years N (%)
Yes	216 (20.5)	455 (23.4)	576 (24.3)	95 (15.3) ***	241 (24.7)	424 (21.2)
No	433 (41.1)	719 (37.1)	882 (37.2)	270 (43.5) ***	362 (37.1)	783 (39.3)
Can't take a stand	404 (38.4)	766 (39.5)	914 (38.5)	256 (41.2)	372 (38.2)	787 (39.5)

Implantation indication and device	ICD indication		CRT **	
	Primary	Secondary	Yes	No
Yes	256 (23.8)	415 (21.7)	184 (26.5) ***	486 (21.2)
No	413 (38.4)	738 (38.5)	244 (35.1)	906 (39.5)
Can't take a stand	407 (37.8)	763 (39.8)	267 (38.4)	902 (39.3)

Post-implantation experiences	Time since implant		Shock experience		Generator replacement **	
	≤5 years	>5 years	Shock	No shock	Yes	No
Yes	485 (23.0)	186 (21.1)	243 (23.6)	419 (21.7)	138 (18.2) ***	533 (23.8)
No	796 (37.7)	356 (40.3)	395 (38.3)	742 (38.5)	309 (40.8)	843 (37.7)
Can't take a stand	829 (39.3)	341 (38.6)	392 (38.1)	767 (39.8)	310 (41.0)	860 (38.5)

Psychological factors	Symptoms of anxiety		Symptoms of depression	
	Yes	No	Yes	No
Yes	111 (23.6)	546 (22.1)	55 (21.7)	605 (22.4)
No	174 (37.0)	961 (38.9)	106 (41.7)	1028 (38.2)
Can't take a stand	185(39.4)	964 (39.0)	93 (36.6)	1061 (39.4)

End-of-life discussions with ICD team	Battery replacement		Illness trajectory		Deactivation **	
	Yes	No	Yes	No	Yes	No
Yes	292 (22.8)	374 (22.2)	267 (24.1)	396 (21.4)	113 (26.3)	549 (21.6)
No	508 (39.6)	632 (37.6)	422 (38.1)	719 (38.8)	174 (40.4)	966 (38.1)
Can't take a stand	483 (37.6)	677 (40.2)	419 (37.8)	738 (39.8)	143 (33.3) ***	1021 (40.3)

Legend: * Of the total, Yes, n = 671 (22.4%); No, n = 1152 (38.5%); Can't take a stand, n = 1170 (39.1%); ** = overall chi-square significant at $p < .05$; *** = post-hoc examination of the standardized residuals was used to determine which cell or cells contributed to the significant difference and those cells marked with a *** exceeded the critical value associated with $p < .05$.

experiences were indecisive about deactivation or ICD replacement. Irrespective of shock experiences, those who could take a stand regarding deactivation chose to keep shock therapies active in many cases. The divergence in attitudes we found in our study reflect the heterogeneity and ambivalence of a large group of ICD recipients in a stable medical condition where psychological states, needs and experiences vary and the conclusion is that "one model" does not fit all.

References

[1] Lampert R, Hayes DL, Annas GJ, Farley MA, Goldstein NE, Hamilton RM, et al, American College of Cardiology, American Geriatrics Society, American Academy of Hospice and Palliative Medicine, American Heart Association, European Heart Rhythm Association, Hospice and Palliative Nurses Association. HRS expert consensus statement on the management of cardiovascular implantable electronic devices in patients nearing end of life or requesting withdrawal of therapy. Heart Rhythm 2010;7:1008–26.

[2] Padeletti L, Arnar DO, Boncinelli L, Brachman J, Camm JA, Daubert JC, et al, European Heart Rhythm Association, Heart Rhythm Society. EHRA expert consensus statement on the management of cardiovascular implantable electronic devices in patients nearing end of life or requesting withdrawal of therapy. Europace 2010;12:1480–9.

[3] Goldstein NE, Bradley E, Zeidman J, Mehta D, Morrison RS. Barriers to conversations about deactivation of implantable defibrillators in seriously ill patients: results of a nationwide survey comparing cardiology specialists to primary care physicians. J Am Coll Cardiol 2009;54:371–3.

[4] Marinskis G, van Erven L, EHRA Scientific Initiatives Committee. Deactivation of implanted cardioverter defibrillators at the end of life: results of the EHRA study. Europace 2010;12:1176–7.

[5] Kirkpatrick JN, Gottlieb M, Sehgal P, Patel R, Verdino RJ. Deactivation of implantable cardioverter defibrillators in terminal illness and end of life care. Am J Cardiol 2012;109:91–4.

[6] Pedersen SS, Chaitsing R, Szili-Torok T, Jordaens L, Theuns DAMJ. Patients' perspective on deactivation of the implantable cardioverter-defibrillator near the end of life. Am J Cardiol 2013;111:1443–7.

[7] Fluur C, Bolse K, Strömberg A, Thylén I. Patients' experiences of the implantable cardioverter defibrillator (ICD); with a focus on battery replacement and end-of-life issues. Heart Lung 2013;42:202–7.

[8] Goldstein NE, Mehta D, Siddiqui S, Teitelbaum E, Zeidman J, Singson M, et al. That's like an act of suicide. Patients' attitudes toward deactivation of implantable defibrillators. J Gen Intern Med 2008;23:7–12.

[9] Kapa S, Mueller PS, Hayes DL, Asirvatham SJ. Perspectives on withdrawing pacemaker and Implantable Cardioverter Defibrillator therapies at end of life: results of a survey of medical and legal professionals and patients. Mayo Clin Proc 2010;85:981–90.

[10] Stewart GC, Weintraub JR, Pratibhu PP, Semigran MJ, Camuso JM, Brooks K, et al. Patients expectations from implantable cardioverter defibrillators to prevent death in heart failure. J Card Fail 2010;16:106–13.

[11] Raphael CE, Koa-Wing M, Stain N, Wright I, Francis DP, Kanagaratnam P. Implantable cardioverter defibrillator recipient attitudes towards device deactivation: how much do patients want to know? PACE 2011;34:1628–33.

[12] Strachan PH, Carroll SL, de Laat S, Schwartz L, Arthur HM. Patients' perspectives on EOL issues and implantable cardioverter defibrillators. J Palliat Care 2011;27:6–11.

[13] Conelius J. The development, refinement, and psychometric testing of the attitude toward advanced directive survey in implantable cardioverter defibrillator patients. J Cardiovasc Nurs 2013;28:238–44.

[14] Herman D, Stros P, Curila K, Kebza V, Osmancik P. Deactivation of implantable cardioverter defibrillators: results of patient surveys. Europace 2013;15:963–9.

[15] Russo JE. Deactivation of ICDs at the end of life: A systematic review of clinical practices and provider and patient attitudes. Am J Nurs 2011;111:26–35.

[16] Thylén I, Wenemark M, Fluur C, Strömberg A, Bolse K, Årestedt K. Development and evaluation of the"EOL-ICD Questionnaire" as a measure of experiences, attitudes and knowledge in end-of-life in patients living with an implantable cardioverter defibrillator. Eur J Cardiovasc Nurs October 2013 [accepted for publication].

[17] EuroQol Group. EuroQol-a new facility for the measurement of health-related quality of life. Health Policy 1990;16:199–208.

[18] Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand 1983;67:361–70.

[19] Kramer DB, Buxton AE, Zimetbaum PJ. Time for a change — a new approach to ICD replacement. N Engl J Med 2012;26:291–3.

[20] Epstein AE, Dimarco JP, Ellenbogen KA, Estes 3rd NA, Freedman RA, Gettes LS, et al, American College of Cardiology, American Heart Association Task Force on Practice Guidelines, American Association for Thoracic Surgery. ACC/AHA/HRS 2008 guidelines for device-based therapy of cardiac rhythm abnormalities. Heart Rhythm 2008;5:e1-62.

[21] Dunbar SB, Dougherty CM, Sears SF, on behalf of the American Heart Association Council on Cardiovascular Nursing, Council on Clinical Cardiology, Council on Cardiovascular Disease in the Young. Educational and psychological interventions

to improve outcomes for recipients of implantable cardioverter defibrillators and their families. A scientific statement from the American Heart Association. Circulation 2012;126:2146–72.
[22] Clark AM, Jaarsma T, Strachan P, Davidson PM, Jerke M, Beattie JM, et al. Effective communication and ethical consent in decisions related to ICDs. Nat Rev Cardiol 2011;8:1–12.
[23] Coventry PA, Grande GE, Richards DA, Todd CJ. Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review. Age Ageing 2005;34:218–27.
[24] Goldstein NE, Lynn J. Trajectory of end-stage heart failure: the influence of technology and implications for policy change. Perspect Biol Med 2006;49:10–8.
[25] Jaarsma T, Beattie JM, Ryder M, Rutten FH, McDonagh T, Mohacsi P, et al, Advanced Heart Failure Study Group of the HFA of the ESC. Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. Eur J Heart Fail 2009;11:433–43.
[26] Markman M. Implications of cancer managed as a "chronic illness.". Curr Oncol Rep 2011;13:90–1.
[27] Buck HG, Zambroski C. Upstreaming palliative care for patients with heart failure. J Cardiovasc Nurs 2012;27:147–53.
[28] Mueller PS, Jenkins SM, Bramstedt KA, Hayes DL. Deactivating implanted cardiac devices in terminally ill patients: practices and attitudes. Pacing Clin Electrophysiol 2008;31:560–8.
[29] Crane M, Wittink M, Doukas D. Respecting end-of-life treatment preferences. Am Acad Fam Physician 2005;72:1263–70.
[30] Goldstein NE, Lampert R, Bradley E, Lynn J, Krumholz HM. Management of implantable cardioverter defibrillators in end of life care. Ann Intern Med 2004;141:835–8.
[31] Berger JT, Gorski M, Cohen T. Advance health planning and treatment. Preferences among recipients of implantable cardioverter defibrillators: an exploratory study. J Clin Ethics 2006;17:72–8.